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ABSTRACT

The symptoms and nature of Tourette Syndrome (TS) and the role of the teacher in educating the child with TS are addressed in this pamphlet, as are other behaviors that may be connected to TS such as obsessive-compulsive symptoms, attention deficit hyperactivity disorder, and learning disabilities. Information on medications for TS is included. Teachers are encouraged to help by fostering feelings of self-esteem in the child with TS and teaching all children tolerance and compassion. Seventeen suggestions are offered for the education of children with TS, including, among others: being aware that the effects of TS on cognitive functioning may vary over time, using caution in interpreting IQ scores and results of standardized achievement tests, working closely with parents, recognizing that most children with TS learn best in a moderately structured classroom, providing children with TS opportunities for physical movement and a refuge for times when symptoms become intensified, understanding that children with TS are not necessarily learning disabled, modifying requirements for written work and allowing extra time to finish assignments, and helping the child with social isolation in the classroom. Brief annotations are provided for four videotapes and four publications on TS. (SW)

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Introduction

"Miss Brown, Mary keeps blinking her eyes, shaking her head and making a funny clucking noise. She says she can't help it. Why doesn't she stop?"

"Mr. Smith, Johnny is disturbing me and I can't concentrate on my work. He is throwing his head and arms around and keeps clearing his throat. He even snorts like a pig. Tell him to stop behaving that way."

An otherwise well-behaved child may suddenly begin yelping, hissing, or barking. Shoulders may twist, arms fly, torsos bend. Is this child looking for attention? Is he emotionally disturbed? Is he a behavior problem? No, these descriptions are not of a child who is emotionally disturbed or a child who is deliberately misbehaving to seek attention. They are descriptions of children with a neurological tic disorder called Tourette Syndrome (TS).

An explanation of what Tourette Syndrome is and how it can be managed in the classroom is offered in this booklet. After reading it a teacher may ask how it's possible to meet the needs of such children in a classroom with 25 or more other pupils. The answer is very simply, "We must." These students have the same needs for companionship and acceptance as anyone else. They are intelligent and also have the same intellectual needs as other children. The school has an obligation to meet these needs – not only a moral obligation, but a federally mandated one as well in the form of Public Law 101-476.

It is important to note that the suggestions made for dealing with the child with TS can be applied to dealings with numerous other "special" students. While the symptoms of Tourette Syndrome are unique, the solutions to the psychological, educational and social problems that arise from the situation have far-reaching applications.

What is Tourette Syndrome?

Tourette Syndrome is an inherited neurological multiple tic disorder. It often emerges in early childhood before the child enters school. The nature of the classroom setting, however, with its inherent restrictions and demands can turn what was already a difficult problem into a nightmarish situation if not handled skillfully. The symptoms are characterized by involuntary body movements and uncontrollable vocalizations and/or verbalizations. For example, the motor manifestations may include blinking, nose twitching, facial grimacing, shoulder, arm or leg jerking. The verbal tics may include hissing, snorting, barking, clucking or more explicit verbal outbursts of words and phrases which erupt without warning.

Sometimes coprolalia (the uncontrollable uttering of obscenities), echolalia (repeating the words of others), or palilalia (repeating one's own words) are associated with Tourette Syndrome as well as compulsive or ritualistic repetitive behavior. The tics and movements of TS change every few months with new ones replacing or being added to the old ones. Research indicates that while tics can sometimes be inhibited for short periods of time, voluntary inhibition frequently causes explosive build-up of other symptoms. There is medication that can help control the symptoms for many, but the relief is only partial and there may be undesirable side effects, some of which interfere with cognitive processes.

Although it has been mentioned in the medical journals since Dr. Gilles de la Tourette identified it in 1885, Tourette Syndrome is still poorly understood and often misdiagnosed. It is most often misdiagnosed as an emotional problem, which it is not. It is difficult enough living with such bizarre symptoms both at home and in a school environment, but imagine how horrendous it must be to twitch, jerk, and yelp uncontrollably without even knowing why your body is doing such strange things. Such is the plight of vast numbers of people with TS, who on the average suffer for 7 to 10 years before they are properly diagnosed.

Although increasing numbers of doctors are now able to accurately diagnose this syndrome (due in great part to the efforts of the Tourette Syndrome Association), a full 80% of all newly diagnosed patients still come to their doctors having diagnosed themselves after reading a popular article or viewing a program about TS. This startling statistic should highlight for educators the importance of the part they can play in identifying students who may unknowingly have Tourette Syndrome.

To make it easier to recognize Tourette Syndrome, the following list has been compiled. A person with TS may exhibit one or more of these tics, depending on the severity of the case:

Eyeblinking	Coughing
Other facial twitches	Echolalia
Head jerks	Throat clearing
Shoulder jerks	Grunting
Arm movements	Other sounds
Finger movements	Stuttering
Stomach jerks	Touching part of body
Kicking	Touching other people
Other leg movements	Touching objects
Low noises	Picking at things (clothing, etc.)
Loud noises	Self-harming behavior
Coprolalia (obscene words)	Low frustration tolerance
Words out of context	Anger, temper fits

Associated Disorders

Children with TS may also exhibit associated behavioral problems which often may be as challenging to their functioning as the tics themselves. Following are behaviors frequently reported to be associated with TS.

Learning Disabilities

Aside from being plagued with uncontrollable movements and noises, some students with TS have accompanying learning disabilities. Understanding how

to deal with the learning disabled child can be confusing for the classroom teacher even without the added complication of the TS movements and noises. While each student must, of course, be evaluated on an individual basis, there are certain general characteristics of the child with learning disabilities that are worth noting.

While he* may be of normal intelligence, he cannot assimilate and remember information in the same manner as other students. He should not be considered "dull" or "lazy" or "careless." Alternate methods are required to reach this child when teaching through the traditional methods proves unsuccessful. The learning environment in any classroom can be adapted to meet the needs of individual students if a teacher is willing to be flexible and creative. For example, assignments can be shortened, time limits can be extended, testing and reports can be given orally.

Young students with learning disabilities often reveal inadequacies in dealing with space, time and directionality. They have difficulty making generalizations, and we should not assume that all children will pick up concepts as easily as others. In fact, many a young child with academic difficulties will also have difficulty learning concepts of socialization that other children absorb naturally. He should not be labeled "bad" or "misbehaved" because of it. The teacher must first determine if he understands what is expected of him.

Teachers and parents consistently note characteristics of impulsivity among this population. Another frequently reported problem is that of perseverance. A student may appear to "get stuck" with an activity or an action. When teachers understand that this is not deliberate misbehaving, they are more likely to have the patience to cope with it. On the other hand, some children with TS have problems "getting started" and might need individualized encouragement. Most students will have great difficulty concentrating, which should be taken into consideration when expectations are formulated for them. This is especially true for students taking medication.

* The pronoun "he" is used to designate both "he" and "she."

Methods of evaluating and reporting on such students should also be modified to meet their individual needs. Imagine how discouraging it is for the child who has worked to his capacity level and made excellent progress for a specific period of time to be given a grade of "D" simply because classmates, who are not coping with a disability, have acquired greater expertise in a particular subject. Progress and acquisition of knowledge for a child with TS should be measured according to his own potential and abilities. An "Individualized Educational Plan" (IEP) for TS students should be created accordingly.

Students sensitive about their learning problems and fearing that they will be laughed at often develop the defensive posture of "class clown." They deliberately act funny and call attention to themselves for silly behavior in the hopes that others will be "blinded by their footwork" and won't notice their true shortcomings. Teachers should be sensitive to this pattern of behavior and deal with it firmly but with kindness. At times children with TS may exhibit subtly puzzling behavior patterns. In these cases, teachers should consult with parents to determine whether or not this behavior is a manifestation of the illness or perhaps a side effect of medication.

Attention Deficit Hyperactivity Disorder

Research shows that as many as half of all children with TS may also have ADHD. ADHD is a collection of behaviors which include impaired ability to focus and sustain attention, as well as problems with impulse control. Students may have trouble sticking to tasks and completing them. They also tend to be disorganized and appear forgetful.

The learning environment can be modified to help such students. Assignments can be broken down into smaller, manageable units. Distractions can be minimized by placing a portable carrel on the student's desk, thus creating privacy. This "private office" often becomes a coveted spot in the classroom, even for students who don't usually have trouble concentrating.

Obsessive-Compulsive Behaviors

Obsessive compulsive symptoms include recurrent unwanted thoughts and repetitive ritualistic behaviors. There may be a need to redo work over and over until it is perfect, a need to "even things up," or a need to check things over and over. Classroom teachers may wish to consult with other professionals to better understand the management of such behavior in the classroom.

Role of the Teacher

Teachers, as well as other school personnel such as nurses, psychologists, guidance counselors, and administrators, can play a vital role in the lives of these students in two very distinct ways. One is in helping to accurately identify new cases and referring them to the proper channels for help. The second is in skillfully handling the child in the educational setting.

The first is easier to achieve, although no less important than the latter. By merely being knowledgeable and informed on the subject and sharing this knowledge with their colleagues, teachers are in an excellent position to save many lives, not from death because Tourette Syndrome is not fatal, but from years of torment and embarrassment, and from the ultimate destruction of all self-esteem and motivation which so often leads to a wasted life.

The second way in which teachers dramatically affect the lives of students with TS, or any student with a special disability or need, is in how they handle the classroom situation vis-a-vis this special child. The two main areas of concern are the psycho-social and the educational, which of course overlap.

Self-Esteem

The most overwhelmingly useful thing a teacher can do for a child with a special problem such as Tourette Syndrome is to foster feelings of self-worth and self-esteem. While this may often seem to be difficult, it is by no means impossible. How wonderful it

would be if more teachers would adopt as their own, the adage, "the difficult we do immediately, but the impossible takes a little longer." It may be difficult at first to get past the twitches and yelps to the "real" child, but it will be worth the effort. Children with TS have positive qualities that can be tapped as a source to bolster their self-image. Does Mark create beautiful drawings and paintings? Can Ellen sing or play an instrument, or write lovely poems? What about Eric's collection of butterflies, or stamps? Aren't John and Susan excellent office assistants – responsible, efficient, trustworthy? A teacher sensitive to a child's need to feel good about himself can find numerous opportunities to promote these feelings. How often have we heard adults relate stories about how a positive contact with a particular teacher changed their lives?

A lesson in social studies is easily forgotten. What is the capital of Paraguay? Who discovered the Mississippi River? But the lessons, "My teacher thinks I'm dumb" or "My teacher thinks I try hard and often do well," are lessons that remain with an individual for his entire life. An aware and sensitive teacher can help teach a child to accept and like himself in the classroom by showing him acceptance and appreciation. Treating a child with sensitivity and respect, when others around him may offer nothing but ridicule and rejection, will have an indelible and positive effect on his life.

A constructive suggestion for increasing a child's self-image would include giving him positive and immediate feedback. Let him know that he's doing a good job and praise him for things you might take for granted with another child. Stress the positive things he does, not the negative. For example, many children with TS have severe handwriting problems. Whereas you might comment that another child's paper "could be neater," why not mention to the child with TS that his writing looks better than his last paper and that you are happy to see him making such an effort at writing. However, if he cannot improve his handwriting, alternatives to writing should be sought, such as oral tests, use of a tape recorder,

computer, or another student to share notes. Students with TS often encounter problems with the answer sheets used on standardized tests. Computer forms requiring blackening of an area with a soft pencil may cause perseveration and prevent students from moving on to the next question. Alternative methods of marking answers should be sought.

Another example of providing positive feedback is to stress how many spelling words he got "right" on the test, rather than how many he spelled wrong. This, by the way, is a very effective teaching technique for ***all*** students.

Compassion

What about tolerance and compassion? Can they be taught to students as history or math can be taught? The answer is yes. And once the lesson is learned, its effect can be carried out of the classroom into the cafeteria, onto the playground, and hopefully much further. The following incident recently observed by an elementary school teacher illustrates how successful a teacher can be in this area. A great deal of noise was overheard outside. On looking through the window to the playground, it was observed that one sixth grade boy was pummeling another in retaliation for being called "a name." The teacher related that what she expected to see next was the surrounding ten boys take sides and proceed to encourage the antagonists with "Let him have it, Mike" or "Give it to him, Rob," as is often the case under these circumstances. What transpired, however, was an unusual and touching scene. The bystanders proceeded to separate the fighters and tried to calm the situation with exclamations of, "You didn't mean it, did you, Mike? Say you didn't mean it," and Cool it, Rob. Give him a break." The teacher further related, "These students are all in Ed's class. Ed is a sixth-grade teacher who insists that students and parents address him by his first name. He is a different sort of teacher. His classroom environment, unlike so many rigid classrooms, is open, accepting, free. Tolerance and goodwill pervade the entire atmosphere. Mike does in fact have a special problem and he is

far from the most popular boy in the class, but obviously the others have been encouraged to develop enough compassion for him to act as they did." When the classroom atmosphere encourages feelings of human kindness, tolerance and compassion, the benefits will accrue to society as a whole. The lesson isn't learned overnight, but is well worth the extended effort.

Very often dislike or rejection of another person is based on fear – usually fear of the unknown. In this case, a teacher who has taken the trouble to understand the limitations or symptomatology of a particular disability can then share with the class the knowledge and confidence acquired. This in turn can help the entire group to overcome a major stumbling block to acceptance. An older student with TS who expresses himself well, recently summed up his desires and frustrations in this way, "All I ever wanted was for my teachers to understand and accept me. Underneath my tics and noises, I'm a person just like anyone else."

Medication

The most commonly used medication to treat TS is haloperidol (Haldol). This medication has many side effects that can impact upon learning processes as well as behavior.

The child taking Haldol might be tired and appear drowsy or irritable. Haldol may interfere with the cognitive processes, most notably short term memory. Another misunderstood behavioral manifestation of taking this medication is depression. Depression is a common side effect, and parents should be alerted when it seems to occur at school. Also, students taking Haldol also have been reported to sometimes develop school phobia (school avoidance and social phobia). The phobic syndromes disappear with discontinuation or reduction of the haloperidol dosage.

Among other medications used for treatment of TS, pimozide (Orap) and clonidine (Catapres) are the

most frequently used. Pimozide has been known to cause side effects similar to Haldol. However, most patients report that pimozide has fewer side effects. Clonidine has been reported to have a positive effect on attention deficit problems related to TS.

Often parents, along with the physican will be measuring how much medication a child needs according to the severity of his symptoms at home. The parent might not be aware that the child's symptoms are milder at school. This often occurs because children who are able to partially inhibit symptoms due to medication, no longer have to "hold them in" when they are with their families and feel very comfortable. Parents and teachers ***must maintain constant communication*** so that a parent will have the benefit of a balanced assessment when trying to determine whether to decrease or increase medication.

The following section is reprinted from a pilot study on the *Cognitive and Educational Implications of Tourette Syndrome* conducted by the Learning Disorders Unit, New York University Medical Center, New York, NY, under the direction of Rosa Hagin, Ph.D. These guidelines which represent a summation of this study are an invaluable tool for any educator working with a student with TS.

Guidelines for the Education of Children With Tourette Syndrome

1. **Look at the whole child — not the disease.** The variation observable even in the small sample of this pilot study underlines the importance of focusing on the whole child, not just the problem; specifically this means assessing the child's strength and resources for compensation, as well as the specific symptoms he/she presents.

2. **Early diagnosis is a crucial factor in the management of these children.** Early diagnosis permits a resolution of the panic, confusion, guilt, and anxiety which beset the family as the symptoms begin to emerge. When a definitive diagnosis is made, the family can turn their efforts in the direction of educational planning and implementation.

3. **Medication should be regarded as an individual matter for the child, his family and the physician to resolve.** This pilot study and the questionnaire responses convinced us of the wide variation in response to medication. It is necessary for the physician to monitor not only the child's response to medication, but also other aspects of the child's functioning as well.

4. **Clear, recent factual information about Tourette Syndrome should be provided to all the people involved in the child's education.** Information about Tourette Syndrome is a crucial matter in educational planning. It is important for **parents** in order that they can keep current as new advances in the field are reported. It is important for **educators** to understand the scope of the problem even when the child appears to be relatively symptom-free at school. Information is important to the **peers** of the child because it can signal the beginning of acceptance and may help the child to avoid the social isolation reported so frequently by the youngsters. Information is important for the **professionals** who seek to help the family; it can enable them to recognize and to assist in the family's search for adequate diagnosis. It will also serve an important role in updating the training of professionals in order to keep them abreast of new developments in the field. Finally, information is important for the **general public** to build acceptance and understanding of the implications of Tourette Syndrome, as well as to serve as-yet unrecognized children with Tourette Syndrome.

5. **Effects of Tourette Syndrome upon cognitive functioning may vary greatly between children and with the individual child over time.** The Syndrome may have effects at different levels of cognitive functioning: A) direct effect of the tics upon specific cognitive tasks, as for example in performing the skilled motor activities required in handwriting or typing. B) indirect effects of the tics as the learner attempts to inhibit symptoms in the classroom. C) medication effects, such as the blunting of cognitive processes asso-

ciated with the use of medications prescribed to relieve the symptoms. D) interpersonal effects resulting from the symptoms which may result in school isolation, rejection and sometimes exclusion from school participation.

6. **Children with Tourette Syndrome need sufficient intellectual challenge.** School is an area in which youngsters with Tourette Syndrome may excel. Their troubles in demonstrating what they know should not prevent them from receiving the most challenging educational experience possible.

7. **Caution should be used in interpreting I.Q. scores as estimates of cognitive potential in children with Tourette Syndrome.** Our data show that formal testing, even on an individual basis, may underestimate what these children are capable of accomplishing educationally.

8. **Caution also is advised in interpreting results of standardized educational achievement tests.** Formal testing of educational achievement, particularly long achievement batteries, may also underestimate the child's accomplishments. Modification in administration of any formal achievement test is necessary. This is particularly apparent with group tests when the pupils must work independently for a sustained period of time. More adequate sampling of these youngsters' achievements can be obtained from the more recently developed individual tests of achievement or from the introduction of rest periods during the administration of group tests.

9. **Parents represent an invaluable resource in the education of children with Tourette Syndrome.** The concordance of school descriptions secured in the course of our pilot study confirmed the parent's accuracy in realistically assessing educational problems. Therefore, educators should draw upon parents' understanding of Tourette Syndrome, as well as their knowledge of their own child's educational needs. Parent service in this regard should represent more than a signature on an IEP to represent compliance with the federal law. It is firmly recommended that

teachers and parents maintain mutual support and ongoing communication.

10. **Most children with Tourette Syndrome learn best in a moderately structured classroom.** Although there are some variations with regard to this recommendation, the group as a whole seemed more comfortable with a moderate degree of structure, something between the open classroom and the more rigid organized traditional classroom. The children need the guidance of clearly articulated directions from the teachers, but they also need the opportunity for independent movement which moderately structured classrooms permit.

11. **Children with Tourette Syndrome need opportunities for physical movement.** The restlessness which they experience, even if they are relatively symptom free, call for opportunity for freely expressed physical activity.

12. **They need a refuge for times when symptoms become intensified.** A resource room, a nurse's office, a library, a counselling office, a school secretary's office – some refuge must be made available at times when symptoms are intense. A private area where the expression of the tic will not be noticed by other people is an important need in educational planning for these children.

13. **Children with Tourette Syndrome are not necessarily learning disabled.** Many, however, do experience problems associated with a learning disability. There should be adequate provision for these children, as for any youngster enrolled in the schools. These provisions might be a resource room, a learning disability classroom, or individual one-to-one help. For those with a learning disability, some compromise between the freedom of movement required by the TS symptoms and the firmer structure requir d for freedom from distraction must be achieved. One should not, however, assume that all children with Tourette Syndrome will have learning difficulties.

14. **Provisions should be made for motor problems associated with Tourette Syndrome, for they are likely to appear in most of the children.** Schools should provide substitutes (a buddy, a teacher aide, opportunity for oral response or use of a tape recorder) in order to help the child compensate. There should be modification of the requirements for written work in order to secure quality responses.

15. **Timing is a crucial issue.** These children need extra time to finish school work. It is, therefore, useful to offer early warnings about time limits and to provide moderately paced instruction. Work can be divided into brief segments. Parents can also be helpful in filling in the gaps which may occur in school work. Teachers also need to be aware of the medication effects and also of the fact that TS symptoms wax and wane. Therefore, what is accomplished quickly on some days will take much longer on others.

16. **Stress effects must be considered in all school settings.** In general, stress exacerbates symptoms. Therefore, the effects of stress must be considered in all learning settings, including competitive sports. The unstructured periods of the day may be sources of stress for these children, and the need for benign adult supervision at such times might be considered. Teachers can also protect youngsters from stress by avoiding abrupt transitions and split-second timing in the classroom. It is more useful to anticipate and help the youngster prepare for stress producing experiences than to have to deal with the consequences.

17. **Many of these children need help with the social isolation they may experience in the classroom.** Nearly all the youngsters reported feelings of isolation in the classroom. Awareness of this interpersonal problem should lead the teacher to avoid situations which emphasize this problem, such as the choosing up of teams. Adults may need to exercise some ingenuity in order to initiate alternative means of including these youngsters in classroom activities.

It should also be remembered that these children will profit from an adult model in the case of social acceptance. The teacher who values the child as a contributing member of the class will be offering the child's classmates an appropriate mature model.

Conclusion

Students with disorders such as Tourette Syndrome, or in fact any atypical condition that sets them apart from their classmates, deserve to be educated in an atmosphere that will allow them to reach their maximum potential. Samuel Johnson, the prominent 18th century literary figure, accomplished his lofty goals despite the intrusion of twitches and compulsions that plagued him all his life. Today, adults with Tourette Syndrome who have themselves gone on to become successful psychologists, musicians and business people often relate how a supportive educational environment helped to compensate for many hardships and contributed to their future successes. An environment that is hostile is a much less effective place to learn and grow than one that is tolerant and accepting.

An Informed and Sensitive Teacher Can Make a World of Difference

ADDITIONAL TSA RESOURCES

VHS FILMS

A Regular Kid, That's Me: An Inservice Film For Educators — A new aid for teachers to help understand the complexities of teaching children with TS. Includes explanation of the complexities of TS and suggests interventions that work.

Stop It! I Can't — For elementary school ages. Written to create sensitivity and reduce ridicule among their peers.

I'm A Person Too — Prize winning documentary featuring five people from diverse backgrounds talking about living with TS: depicts the broad range of symptoms.

Tourette Syndrome: The Parent's Perspective — Diplomacy In Action — Features E. Collins, Ph.D. and R. Fisher, M.Ed., providing guidance to TS families on school advocacy issues.

LITERATURE

Coping with TS — A Parent's Viewpoint — E. Shimberg. Covers parental and family acceptance, behavior management. (Revised 1993)

Problem Behaviors & TS — Drs. R. Bruun, and K. Rickler. Describes recent research and what is now known about the relationship of a variety of behaviors and TS. Contains helpful advice by Emily Kelman-Bravo, CSW, MS about the management of problem behaviors for families and individuals with TS. (Revised 1993)

Discipline and the Child with TS: A Guide for Parents and Teachers — R. Fisher-Collins, M.Ed., 1993. Helps children redirect impulses and compulsions through teaching cause and effect relationships. Included are techniques for disciplining children without the use of aggression or intimidation.

An Educator's Guide to Tourette Syndrome — S. Bronheim, Ph.D. Covers symptoms, techniques for classroom management, attentional, writing and language problems.

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